Young Adults’ Discursive Constructions of Chronic Illness Experience: Accounts of Type 1 Diabetes and Inflammatory Bowel Disease (IBD)

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ABSTRACT
This thesis investigates the experiences of young adults living with either type 1 diabetes (T1DM) or Inflammatory Bowel Disease (IBD), two chronic conditions which are prevalent among this age-group. This is set against the long tradition of research into chronic illness experience; however, young adults are commonly underrepresented in this area, in spite of the contention that the new-found pressures and responsibilities associated with this life-stage may be especially difficult to manage alongside a chronic condition (Arber and Ginn, 1998).

In addressing the central research question – ‘how do young adults discursively construct their individual experiences of chronic illness?’, semi-structured interviews were carried out with respondents aged 18-29 (n = 30). Transcribed interviews were subject to open-coding using qualitative software, which led to the systematic identification of predominant themes for analysis. Data was considered primarily as ‘accounts’ (Radley and Billig, 1996), with a focus on the moral-underpinnings of the respondents’ talk. These accounts were examined from a rhetorical discourse analysis perspective (Arribas-Ayllon et al., 2011), which entailed micro-investigation of the discursive devices drawn upon by the respondents in representing their experiences as part of situated identity-performances (Riessman, 1990). This approach of combining methods of coding to systematically identify predominant themes, with fine-grained discursive analysis of lengthy stretches of talk is unique in chronic illness experience research.

Across the predominant themes identified (self, other-orientation and control), some similar trends were identified, but also considerable variation, most significantly across the two conditions. In relation to self, accounts of T1DM showed greater evidence of ‘transformational’ experiences, and the gaining of positive self-images, with respondents constructing greater levels of agency regarding the integration or distancing of illness vis-à-vis selfhood, whereas in accounts of IBD ‘loss of self’ (Charmaz, 1983) was more prominent. In accounts of other-orientation, those with IBD more commonly constructed ‘felt stigma’ and ‘enacted stigma’ (Scambler and Hopkins, 1986) than T1DM-respondents, which had implications for reported disclosure practices vis-à-vis the two conditions. ‘Enacted deviance’ (Scambler, 2004) was also more commonly constructed by IBD-respondents, in reported cases where the signs and symptoms of their condition became outwardly perceptible. Within the theme of control, T1DM-respondents generally constructed greater condition control and lifestyle control than IBD-respondents. Variation was also observed in reported management-strategies, which reflected the respondents’ differing conceptions of their ‘healthy bodies’ (Balfe, 2009) – those with T1DM focused on future health concerns, their ‘longer-term’ healthy body, whereas IBD-respondents’ concerns centred primarily on more immediate health consequences, their ‘short-term’ healthy body. These differing conceptions of the ‘healthy body’ influenced how respondents accounted for their ‘risky’ social drinking
practices, with IBD-respondents producing ‘justifications’, and those with T1DM primarily constructing ‘excuses’ (Scott and Lyman, 1968).

In spite of this variation, a consistent thread running throughout the data was the constitution of the morally-driven self. A range of different moral figures were constructed by the respondents, allowing them to perform positive identities throughout. This eased the tension borne out of the conflict between the priorities, desires and demands of young adulthood and the complex considerations surrounding chronic illness, which often meant that the respondents’ reported-behaviours conflicted with medical advice.

In addition to furthering knowledge within the research field, it is hoped that the findings presented in this thesis – especially the representations of different management-strategies, the construction of (lack of) stigma, and representations surrounding social drinking practices – can have implications regarding the advice given to young adults with type 1 diabetes and IBD, both inside the healthcare setting, and as online resources.

REFERENCES


